



Mark Zatyryka's Testimony on Bill 5251

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My name is Mark Zatyryka and I live in West Suffield, CT. I was born with Severe Hemophilia A. Hemophilia is a bleeding disorder. So I was born missing a protein in my blood, so my blood cannot form clots to stop bleeding, usually internal bleeding into muscles and joints. Hemophilia is an extremely painful disorder. I've been on oxycotin, morphine, oxycodone, vioxx, and methadone. None of them could touch the pain I feel when I have an active bleed. I also have chronic pain, every day, from the damage all the bleeding has done to my body. I can't straighten either of my arms and whenever I'm ready, my surgeon has recommended full joint replacements for my left and right elbows and my left and right shoulders.

In addition to the pain, hemophilia is very much a life threatening illness. A hard hit to my head or my internal organs, could be enough to kill me.

While its not easily administered, we are so fortunate to have medication, called factor. I have to infuse, intravenously my factor every-other day. If something goes wrong or I need surgery, I could need factor twice a day every day.

I'd also like to point out that when I was around the age of two, I was infected with HIV, which later developed into AIDS, from my factor.

While it can be a pain to have to infuse every other day, I am so grateful to have access to my medication. It has been such a miracle to all people living with hemophilia to have access to this medication. We are able to go to school, go on vacations, hold a career, and even start a family. I still can't believe that one year ago from next week, my wife and I had twin baby girls, Elliana and Colby. Just a few decades ago, even in the seventies, none of those things were options for someone with hemophilia. You basically lived in the hospital. Your only friends were either nurses, doctors or other patients.

Unfortunately, our community, and many other families living with other high-cost medications, could be potentially going back to those sad dark days.

Many health insurers have implemented, or are considering implementing these specialty tiers where instead of having a reasonable copay and coinsurance, they are requiring their subscribers to pay 20% to 30% of the cost of the medications! According to Health Policy Briefs, from 2012 to 2013 "specialty tiers" increased 65% among private plans.

This is why I'm here today asking you to please pass Bill number 5251, an act limiting out of pocket expenses for prescription drugs.

In order to control cost, or let's be honest, increase their already huge profits, health insurance companies are choosing to increase their profits on the backs of the sickest of the sick. The drugs that are on these specialty tiers are the high-cost specialty drugs that are usually needed for severe chronic illnesses and other life-threatening diseases such as leukemia, multiple sclerosis, rheumatoid arthritis, lupus, Crohn's disease, cancer, HIV/AIDS, and yes, hemophilia.

My factor, to treat my hemophilia, will cost about \$400,000 a year. Before the ACA, I could have been responsible for \$120,000 of that. Luckily the ACA has but a cap on out of pocket expenses, but that cap is almost \$13,000. That \$13,000 can be about half of someone's take home salary. I know many families that live off \$30,000 salaries. These families will need to make the choice of taking their life-saving medication as prescribed, or feed their children.

As I mentioned earlier, I have two daughters. If it came down to them eating and getting what they need, or me taking my medicine, I can promise you, I would roll the dice and hope I don't get sick and have too many bleeds that leave permanent damage.

Bill 5251 would cut that \$13,000 in half and families will only have to pay just over \$6,000...which is still a lot and more than I would want it to be, but compared to \$13,000 it will make a huge difference.

This is a real problem we are facing. This high out of pocket plans have already been shown to lower medication adherence, and lead to worse health outcomes, which is estimated to cost the United States of America \$290 billion annually. And here in Connecticut, each metal tier in our exchange includes a tier 4 formulary with CT citizens having to pay 20%, 30% and even 40% of the cost of their medication.

Lastly, as a person with multiple life-threatening illnesses, who relies on medication which could be on a specialty tier, the people needing these specialty drugs, NEED them. These are NOT elective therapies. These are NOT drugs people choose to be on. I was born with hemophilia. Trust me, I did not ask for it. And now, my whole livelihood and the lives of my family including my two baby girls, is at risk because at any point, my employer could pick one of these plans with specialty tiers. Having to shell out \$13,000 within the first month or two of the year, every year, can sink families, destroy homes, move everyone over to Medicaid so the taxpayers will have to cover the bill, and really hurt our communities. One of the biggest reasons divorce is so common in families with children living with severe illnesses is because of the financial constrain these families go through. And there is no reason for it. Avalere Health estimated the financial impact of a bill similar to this one showed people's annual premiums would increase on average to be \$3 for plans with specialty tiers. Three dollars.

We need to encourage compliance and adherence. Study after study shows not only way better health outcomes as a result of compliance, but also decreased costs. This trend is bringing us in the opposite direction. It is not ok to stick these huge out of pocket bills on these families who are already devastated by cancer and hemophilia and MS and the list goes on and on. These are the families we should be lining up to help.

Thank you for your time.